

A fair trial? Assessment of liver transplant candidates with psychiatric illnesses

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ABSTRACT

Allocating scarce organs to transplant candidates is only one stage in the long process of organ transplantation. Before being listed, all candidates must undergo a rigorous assessment by a multidisciplinary transplant team. The Department of Health and NHS Blood and Transplant (NHSBT) are responsible for the development of detailed strategies to ensure a fair and objective assessment experience for all transplant candidates. Difficulties arise when particularly vulnerable candidates, such as candidates with psychiatric illnesses, are assessed. NHSBT has already developed unique assessment guidelines for alcoholic and substance-abusing liver transplant candidates to allow for a more comprehensive evaluation, but candidates with psychiatric illnesses are still assessed against general criteria. Should these candidates be assessed against their own criteria? On what clinical grounds do transplant teams justify excluding such candidates from transplantation? Is redress available for candidates who feel they have been unfairly refused a liver transplant simply because of their psychiatric illness? This essay will critically examine the provisions published by the Department of Health and NHSBT for the assessment of liver transplant candidates with psychiatric illnesses, and will provide a commentary as to whether enough is being done to protect these particularly vulnerable candidates from inconsistent assessment decisions.

INTRODUCTION

The field of organ transplantation is rife with ethical complexities. Liver transplant candidates come with numerous medical, social and psychological needs, and they must undergo a rigorous physical, psychological, social, environmental and financial assessment (including an examination of their lifestyle choices, attitudes, employment and criminal history, morality, social habits and motivations). Multidisciplinary transplant teams therefore need a comprehensive collection of guidelines at hand to enable them to assess each candidate fairly, objectively, and without prejudice.

To ensure transparency during the process, the Department of Health has published a collection of National Transplant Standards for heart, lung, liver and pancreas transplants, leaving NHS Blood and Transplant (NHSBT) free to develop its own detailed assessment strategies (in more detail below). Ideally, candidates with psychiatric illnesses should be assessed separately from all other candidates using specialist criteria. This would allow transplant teams to consider psychiatric illnesses openly and against agreed clinical benchmarks; to distinguish candidates with

psychiatric illnesses from candidates with anti-social problems; and provide specific forms of redress to candidates who feel they have been unfairly excluded from treatment because of their psychiatric condition. Sadly, none of these ideals are currently realised and this issue has not been canvassed in any detail before.^{1 2}

What follows is a detailed examination of the current assessment guidelines for liver transplant candidates with psychiatric illnesses and a commentary on whether the Department of Health and NHSBT do enough to protect candidates with psychiatric illnesses from unfair decisions.

ASSESSMENT OF LIVER TRANSPLANT CANDIDATES WITH PSYCHIATRIC ILLNESSES

Considerable headway has been made in developing customised assessment policies for alcoholic and illicit drug-using candidates.^{3 4} Can candidates with psychiatric illnesses expect the same approach?

The Department of Health's National Liver Transplant Standards

In 2005, the Department of Health published its National Liver Transplant Standards to develop strategies for patient care, transplant team structure, assessment, transplantation, training and research.⁵ The National Standards declare that candidate assessment must be 'objective, fair and equitable', but this ideal does not translate into a formal standard.⁶ What exactly does the Department of Health recommend for the assessment of liver transplant candidates with psychiatric illnesses?

Transplant teams are advised that because of the shortage in organs, candidates with less than a 50% probability of surviving 5 years after liver transplantation should not be placed on the waiting list.⁷ This '50%/5-year rule' applies to all candidates, and it includes a detailed review of the candidate's physical and psychological condition to determine whether s/he is sufficiently fit to survive long term.⁸ These provisional guidelines suggest that any psychiatric condition must be sufficiently serious to directly affect a candidate's long term survival rate. However, because psychiatric conditions affect candidates in different ways, these guidelines do not rule out any particular condition, however minor.

The Department of Health provides a comprehensive list of specialists who *should* form a transplant team, and these include a psychiatric liaison nurse and a social worker.⁹ A range of psychological and social support services should also be offered at specialist centres.¹⁰ The role of the psychiatric liaison nurse is particularly interesting. According

to the Department of Health, the psychiatric nurse must: be experienced in the management of candidates who abuse alcohol and drugs¹¹; be responsible for the assessment and counselling of candidates with psychiatric problems¹²; and advise the transplant team about candidates who need further psychiatric assessment or further care from local psychiatric services.¹³ The Department of Health has placed a significant burden onto the shoulders of one specialist, and it is rather disappointing that no further guidance is provided as to how a psychiatric liaison nurse would assess and counsel candidates. NHSBT are left with limited guidance as to how to develop a dedicated system of psychiatric care for liver transplant patients, including specialist assessment criteria and post-transplant care.

The Department of Health does provide redress for candidates who are unhappy with their assessment decision. The National Standards recommend that candidates determined as 'unsuitable' for transplantation should be carefully counselled about the reason for this decision, offered the best possible alternative treatment and advised of their right to seek a second opinion at another centre.¹⁴ This recommendation by the Department of Health is an important cornerstone in the assessment of vulnerable candidates, as it encourages transplant teams to justify their decisions. However, this recommendation will only provide limited relief for candidates, as the decision of the transplant team will not be questioned, investigated, changed or over-ruled—the candidate will simply have a choice to go elsewhere. This will be of little consolation to the candidate who feels s/he has been unfairly excluded from transplantation because of his/her psychological condition and not given the fair clinical assessment that s/he deserves.

Finally, the Department of Health make provisions for post-transplant social support for vulnerable candidates.¹⁵ The recommendation simply states that each centre should have a documented social support system to aid post-transplant care in the community, leaving it open to interpretation how exactly candidates with psychological disorders will be taken care of by NHSBT once they return home and how this will influence their chances of transplantation. Would a severely mentally disabled candidate, for example, receive an exceptional post-transplant care package to enable him to undergo surgery and to allow his graft to succeed, or will his transplant team simply deem him unsuitable for transplantation because his psychological condition is too acute to cope with post-transplant care? It is not clear in the National Standards how far NHSBT must go to accommodate candidates with severe psychiatric illnesses, both before and after transplant.

NHSBT's liver transplant candidate assessment protocols

In response to the Department of Health's National Liver Transplant Standards,¹⁶ NHSBT and the Liver Advisory Group published their Protocols for Adults Undergoing Liver Transplantation in 2009, a 12 page document outlining liver transplant candidate assessment and allocation strategies.¹⁷ Interestingly, NHSBT highlights a number of candidates who will require a unique approach to assessment and these include those with psychiatric conditions,¹⁸ but guidance is brief and provides little hope for those seeking a comprehensive assessment experience.

The strictly economical '50%/5-year rule' from the National Standards is enshrined in NHSBT's 2009 Protocols, but with a new and complicated twist:

Candidates should be accepted for transplantation only if they have an estimated probability of being alive 5 years after transplantation

of at least 50% with a quality of life acceptable to the candidate. Other medical criteria and social factors (such as alcohol or drug misuse, age or antisocial lifestyle) are not directly relevant other than whether they affect the above criteria.^{19–21}

NHSBT have complicated things with the 'quality-of-life' criterion. 'Quality' is a notoriously difficult factor to measure in a clinical context. Reservations have been raised in the past about calculating 'quality-adjusted life-years' when allocating scarce medical resources.^{22–24} It must be noted, however, that the 'quality' criterion is used in a subjective context, and it is the *candidate* who decides whether his or her quality of life after transplant would be adequate. This may work well for the majority of liver transplant candidates, but is it fair to candidates with psychiatric illnesses? Candidates with severe psychiatric illnesses often lack the ability to make informed medical decisions, meaning that the transplant team will have to judge the 'quality' criterion for themselves. Some transplant experts may argue that candidates with psychiatric illnesses already possess a substandard quality of life in comparison with other candidates, particularly if they are severely disabled and require full-time care or are not aware of their surroundings. A candidate who cannot communicate, clothe, feed, cleanse or mobilise him or herself before transplant may not show an improvement in his or her quality of life after transplant, even if he or she was predicted to survive beyond the 5-year post-transplant benchmark. As a result, a transplant team may not be able to predict an acceptable quality of post-transplant life for the candidate, or may decide that the candidate's 'substandard' existence will simply become even more traumatic. Candidates with psychiatric illnesses may therefore face exclusion from transplantation through failing to meet the 'quality' criterion which was originally designed for the assessment of more competent candidates.

NHSBT moves on to confirm that a psychiatrist will make up part of the transplant team and it lists other factors which will need to be assessed, including the reason which gave rise to the primary cause of liver failure and psychiatric conditions.²⁵ There are two interesting omissions here. First, although psychiatric conditions are listed, there is no mention of a psychiatric liaison nurse, as suggested by the Department of Health, who may be especially useful to the transplant team when assessing and counselling candidates with social, behavioural or addictive psychiatric problems. It is not made clear by NHSBT what role the psychiatrist will play and how far the transplant team will go to support the far-reaching needs of candidates with psychiatric illnesses. Second, because psychiatric conditions are expressly adopted by NHSBT as part of the liver transplant candidate assessment process, comprehensive guidelines now need to be provided to enable transplant teams and their psychiatrists to fairly and objectively assess a candidate with a psychiatric illness and his ability to undergo the transplant procedure. At this point, the 2009 Protocols direct transplant teams towards two smaller, independent assessment guidelines for alcoholic and illicit drug-using candidates.^{3 4} There are no guidelines available for candidates with psychiatric illnesses or any other mental health conditions. Instead, the 2009 Protocols contain the following single statement:

Concurrent psychiatric conditions are relevant if they will affect the candidate's quality of life or prospect for survival post-transplant. Where uncertainty remains, evaluation should be considered in discussion with other transplant centres and, where appropriate, the Associate Medical Director of NHSBT or the Chairman of the Liver Advisory Group.²⁶

This brief statement is the only official assessment guidance available from NHSBT to assist transplant teams in the complete assessment of liver transplant candidates with psychiatric illnesses. It is woefully inadequate. To begin with, it has not been made clear what would qualify as a 'psychiatric condition'. What if a candidate was simply depressed, stressed or forgetful, or showed signs of extreme anti-social behaviour? Could these characteristics preclude transplantation too? Second, NHSBT states that a psychological condition is relevant only if it affects a candidate's quality of life or survival rate. Part of this recommendation wades once again into the murky waters of 'quality'. It would be extremely difficult to measure in clinical terms the effect of a candidate's psychiatric condition on his/her quality of life. However, as a feasible alternative, perhaps measuring the effect of the candidate's psychiatric condition on his/her post-transplant survival rate would be far simpler? For example, if a candidate is predicted to carry a high post-transplant mortality as a direct result of his/her advanced schizophrenia, then the transplant team could take the schizophrenia into account as a physical factor to be measured clinically, saving the candidate from being excluded from transplantation on indistinct grounds. Even then, however, it is not entirely clear how a psychiatric condition of any kind could adversely affect a candidate's survival rate after transplant. Might the candidate fail to take his/her medication or fail to understand his/her predicament? His/her full-time carer might also need additional help and the candidate might be so emotionally overwhelmed by the whole procedure that some other physical ailment might result (ie, shock). If so, are these criteria sufficiently grave enough to exclude a candidate from life-saving treatment when the Department of Health instructed that a 'documented-support system' should be available for all candidates to aid post-transplant care in the community?¹³ Ideally, a candidate's post-transplant complications and prospects should be calculated against quantifiable clinical criteria only, to allow for consistency, accuracy and fairness.

A third cause for concern is the suggestion by NHSBT that if uncertainty remains over psychiatric candidates, a discussion should take place between transplant centres and the associate medical director of NHSBT or the chairman of the Liver Advisory Group. It is rather telling that NHSBT have made provisions for instances in which uncertainty prevails. If uncertainty is expected to be a recurring problem, why not develop independent assessment criteria for liver transplant candidates with psychiatric illnesses? It seems astonishing that a transplant team can accept a candidate with a psychiatric illness into the liver transplant candidate process with no assessment strategy. There are no guidelines available to direct or instruct the psychiatrist in the transplant team, who might be required to deal with additional psychological, emotional, social and behavioural issues as well as an acute psychiatric illness, and the candidate is offered no redress if an inequitable decision results. The following details are also unclear: first, how severe must a candidate's condition be to render him unsuitable for transplantation? The 2009 Protocols state that his/her quality of life or survival rate after transplant must be affected, but it is not clear what 'affected' means or how serious the risk to quality or survival should be. Second, how are the different types of psychiatric conditions separated by NHSBT to enable each candidate to receive the correct type of assessment? Candidates may be filtered into different groups according to the seriousness of their psychiatric condition, such as 'stress disorder', 'minor mental impairment' or 'serious mental disability'. If this reflects current practice, the criteria against which candidates are

grouped and assessed are not clear. Third, and most importantly, what are the formal exclusion criteria (ie, official contraindications) for liver transplant candidates with psychiatric conditions? In the independent alcoholic and illicit drug-using assessment guidelines, contraindications to transplantation are listed in bullet-point form and include repetitive episodes of non-compliance with medical care, unexplained incidences of past non-compliance, and failure to comply with the assessment or treatment process.^{27 28} What clinical grounds do transplant teams formally use to justify excluding candidates with psychiatric illnesses from liver transplantation? This detail is crucial, because an agreed and well-established list of contraindications will provide candidates with an objective justification for their exclusion from life-saving treatment and it promotes consistency within the assessment process.

A fourth and final detail requires clarification. Without a collection of quantifiable clinical assessment criteria available for candidates with psychiatric illnesses, how will a discussion with the associate medical director of NHSBT, who knows nothing about the candidate and his/her needs, fairly decide what happens to the candidate? This recommendation may have been inserted into the 2009 Protocols to compensate for a lack of detailed policies, but it simply encourages further discretion, ambiguity and inconsistency. If NHSBT's assessment strategies for candidates with psychiatric illnesses were satisfactory, there would be no need to seek the opinion of the director of the organisation to make the final decision. Interestingly, this 'safeguard' does not appear in the independent alcoholic or illicit drug-using guidelines.

CONCLUSION

NHSBT's 2009 Protocols for Adults Undergoing Liver Transplantation provide transplant teams with a brief collection of candidate assessment guidelines that do little to ensure a fair and consistent assessment experience for candidates with psychiatric illnesses. This puzzling lack of guidance is unfortunate, as the assessment of vulnerable candidates is one of the most contentious issues in liver transplantation.

The 'quality-of-life' criterion in the 2009 Protocols is an unnecessary addition to the Department of Health's National Liver Transplant Standards. Even competent candidates will find it difficult to evaluate in clinical terms how a liver transplant will affect their quality of life, but for candidates with psychiatric illnesses, an assessment of how their illness will affect their quality of life and their prospects for survival both before and after transplant is incalculable and inequitable. The primary concern overshadowing the 'quality' test is that a negative decision by a transplant team could label frail or vulnerable candidates as 'substandard'. In a field where ethical dilemmas are prevalent, this is not a suitable criterion against which to assess the fitness of transplant candidates. The quality-of-life test is also subjective, meaning that a candidate with a severe psychiatric illness may not be able to communicate to his/her transplant team what s/he finds acceptable. If this difficult decision is left to the transplant team to make, they might be obliged to take the stricter approach and exclude the candidate from transplantation in support of an economical liver allocation system. No formal contraindications are available against which to justify such a decision. In the absence of any detailed clinical assessment criteria for candidates with psychiatric illnesses, would it not be a better idea to remove all 'quality' considerations from the calculation of the candidate's post-transplant survival rate?

Equal opportunity is important to NHSBT, which defines 'equity' in its 2009 Protocols as 'each candidate within defined categories having an equal chance of being accepted'.¹⁷ This definition of equity is rather odd. It states that in order to be treated equally, candidates are separated into similar groups and then assessed on an equal playing field once inside that group. In practical terms, this means that all candidates with psychiatric illnesses are treated the same as each other, but differently from other candidates. If this is the case, separate assessment protocols should be produced for these candidates (as they have been for alcoholics and illicit drug users).

The Department of Health's '50%/5-year rule' is more than adequate to measure a candidate's physical and psychological eligibility for liver transplantation without the need for a 'quality' assessment. The evaluation of psychiatric illnesses will remain a measured part of the assessment process through this test, but how exactly psychiatric illnesses are assessed by NHSBT still remains a mystery. Candidates with psychiatric illnesses who are about to be assessed will have great cause for concern over the ambiguous nature of NHSBT's 2009 Protocols for Adults Undergoing Liver Transplantation.

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